

Growing Up and Growing Well with IBD

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Estimated that 1 million Americans have Inflammatory Bowel Disease (IBD)

- 100,000 are children
- Most common to develop between the ages of 15-35
- In children less than 10 years of age, Ulcerative Colitis (UC) more common than Crohn's Disease (CD)

Exact cause of IBD is not known. Several factors seem to contribute:

- Familial: Children with IBD may have a relative with IBD
- Genetic Predisposition: Gene has been identified in CD, although not all individuals with CD have this gene type and not all individuals with this gene have CD
- Overactive Immunological Response: The inflammation associated with IBD develops due to an overactive immunological response in a susceptible host

Children with IBD are different from adults because children have unique management needs including consideration of:

Growth and Development:

Important in regard to both physical growth (weight/height) and pubertal development CD can be associated with poor growth most often due to lack of appetite which leads to poor caloric intake. There may also be nutritional losses secondary to diarrhea and malabsorption

- Body image is extremely important in childhood and requires special consideration including:
 - Growth delay and the impact of being smaller than peers
 - Delay of the onset of puberty
 - Side effects of medications especially steroids (acne, weight gain, moon face, stretch marks)
 - Surgical scars

Nutrition:

- Children usually achieve their adult height by age 18
- Good nutrition is essential to help them reach their genetic height potential
- Eating is a social activity, especially with adolescents
- There is no special diet for IBD
- In general, encouraging a balanced diet with sufficient calories is all that is required
- Multivitamin with minerals may be helpful, but not if taking multiple medications is already a problem

Nutrition - Special Situations:

- Supplemental nutrition is used for children who have poor appetite which is affecting their growth. Special diets may also be used for bowel rest
- Nutritional supplements: these are drinks that can be taken by mouth or overnight via nasogastric tube feedings (may be done at home). These supplements are used in addition to meals to increase the child's overall caloric intake
- Elemental Diets: Predigested liquid nutrition used to provide bowel rest. It is not very palatable and often is given via a feeding tube. The child must be very motivated since regular food is often excluded
- Total Parental Nutrition (TPN): Intravenous (IV) nutrition via a special IV catheter which may be done at home or in the hospital. Usually used if liquid nutrition by mouth is not tolerated or to provide complete bowel rest

Other therapies:

- Iron supplementation
- Calcium supplementation
- Omega 3 fatty acids-fish oil

Medications: Types of medications used in IBD include:

Anti-inflammatory:

Steroids

Aminosalicylates (5ASA):

- Mesalamine (Asacol[®], Pentasa[®], Rowasa[®])
- Sulfasalazine (Azulfadine[®])
- Balsalazide (Colazol[®])

Antibiotics:

- Ciprofloxin (Cipro)
- Metronidazole (Flagyl[®])

Biological:

- Infliximab (Remicade[®])

Immunomodulators:

- 6-mercaptopurine (6MP, Purinethol)
- Azathioprine (Immuran[®])
- Methotrexate

Medication Challenges in Children:

- Can they swallow pills? Some medications may be compounded by a pharmacist and some may not

Not being able to swallow pills may prevent the use of certain delayed-release medications i.e. Asacol®/Entocort®

- Does the dosing schedule fit in with their activities?

Some medications need to be taken more than twice a day therefore, it may be necessary to receive it in school

- Is the child ready to take responsibility for taking their own medications?

- Routes of Administration:

Rectal medications can be very effective in certain cases, but may not be easily accepted, especially with adolescents

When using IV's or injections it is often helpful to use topical anesthesia to minimize discomfort

- Compliance may be a problem especially in adolescents because:

Reminder that they have a chronic illness

Forget, especially with more than twice a day dosing

Medication may taste bad

Interactions with alcohol

Once in remission, they feel good and don't see the need

During flare "it doesn't work anyway" attitude

Adolescents are risk takers and test limits

Issues of control

Undesirable side-effects, especially with steroids (acne, weight gain)

Medications - New and Novel Therapies:

- New drugs are formulated for adults (first healthy and then targeted population)

- Few drugs are tested on children therefore indications and dosing are extrapolated from adult studies

- Children's growth and metabolism are different from adults potentially affecting the drug's safety with children

Family Dynamics:

- All family members are affected by having a child with IBD, so take time for yourself and for siblings

- Coping with a chronic illness is a marathon not a sprint, so take your time

- Create a supportive environment by selectively disclosing the diagnosis with family, friends and school

- Allow children to participate in decision making and as they grow to partner with you and their health care providers

- Encourage children (and siblings) to ask questions and answer them honestly

School/Peer Pressure:

- School absences can put children at risk both academically and socially

- IBD is a difficult condition for children to explain and share with others

- It would be helpful to inform teachers/school nurse since children with IBD often need to leave the classroom urgently to use the bathroom

Our Goals for Children Growing up and Growing well with IBD:

- To allow them to achieve their goals and aspirations
- To encourage them to participate in desired activities
- To partner with children and their families to manage the disease
- To work together to find a cure